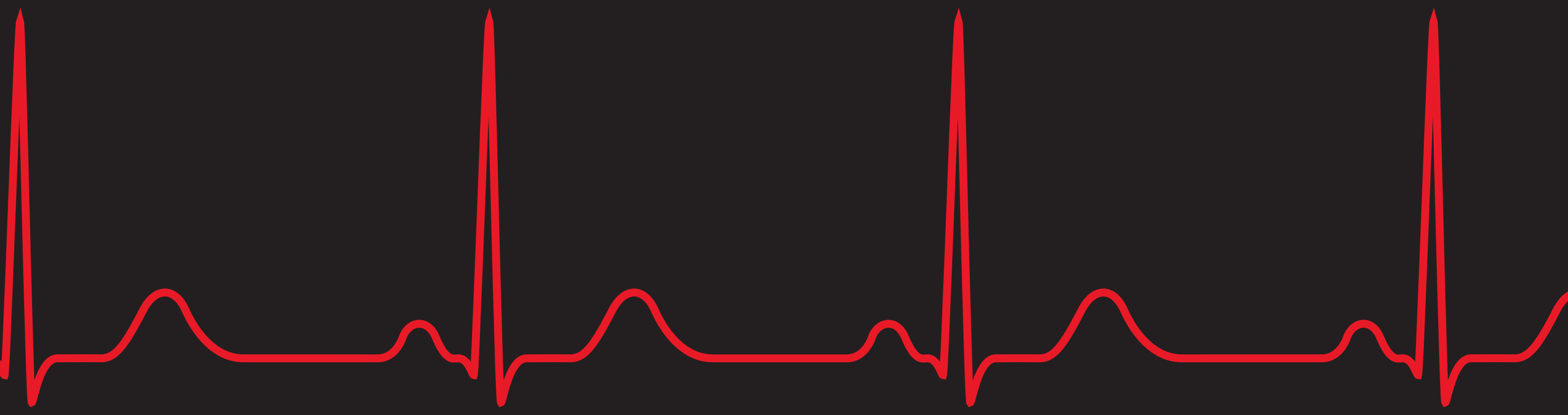
Deactivation of implantable cardioverter-defibrillators towards the end of life

A guide for healthcare professionals
from the Resuscitation Council UK
the British Cardiovascular Society and
the National Council for Palliative Care



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Introduction

Implantable cardioverter defibrillators (ICDs) can prolong life by terminating life-threatening cardiac arrhythmia (ventricular fibrillation [VF] and ventricular tachycardia [VT]) in people at risk of cardiac arrest and sudden death. Some episodes of VT may be interrupted by the device delivering a burst of rapid pacing to the heart, but termination of VF and of some episodes of VT requires delivery of an electric shock to the heart.

Most ICDs also function as a pacemaker that will maintain heart rate in the event of spontaneous bradycardia. Some ICDs are combined as a single device with a biventricular pacemaker, used to synchronise contraction of the left and right ventricles (cardiac resynchronisation therapy [CRT]) and thereby reduce symptoms in some people with heart failure. These are referred to as CRT-D devices. The pacemaker and ICD functions of every device are programmable independently of each other.

As the indications for ICD implantation have expanded, the number of people with ICDs has increased progressively. As a result, more people have survived longer with ICDs and some of those people approach the end of their life, either due to progression of their heart disease to an advanced stage (usually advanced heart failure) or due to development of another irreversible terminal condition. Providing such a person with high-quality end-of-life care and allowing them a dignified death requires consideration and discussion of deactivation of the shock function of their ICD. When the ICD is not deactivated in this way the person may receive multiple painful or distressing shocks from the device during the last hours or days of their life. In some instances the device may delay the person's natural death with shock delivery that the patient would not have chosen to receive if they had been given a chance to discuss deactivation.

The purpose of this document

This document is provided as a guide for healthcare professionals caring for a person who is approaching the end of their life with an active ICD. It aims:

1. To promote high-quality care of patients who are approaching the end of life with an ICD in place by avoiding unwanted prolongation of life and the unnecessary distress that ICD shock therapy can cause in this setting;
2. To outline the circumstances in which ICD deactivation should be considered and/or carried out as part of end-of-life care;
3. To highlight the need for all doctors, physiologists, nurses and other healthcare professionals to consider and discuss ICD deactivation at the most appropriate time, preferably prior to a crisis situation;
4. To explain the relationship between decisions to deactivate an ICD and anticipatory decisions about whether or not to attempt cardiopulmonary resuscitation (CPR);
5. To outline what to do when a patient with an ICD requires deactivation of their device;
6. To promote and guide good communication and documentation in relation to discussions and decisions to deactivate an ICD.

Deactivation (and later reactivation) of an ICD may be needed in other clinical settings (e.g. during operations and other procedures). This document does not address those indications.

When to consider and discuss ICD deactivation

When people are approaching the end of their life their priorities for their care and treatment often change. The General Medical Council (GMC) recommends that people are given the opportunity to plan aspects of their care in accordance with their needs and preferences. In general it is recommended that such advance care planning be considered during the last year of life. However the variable certainty with which prognosis can be predicted accurately must be recognised, so that support is provided to patients and those close to them to help them deal with that uncertainty.

For people with ICDs (including cardiac resynchronisation therapy-defibrillator [CRT-D] devices) who are approaching the end of their life advance care planning should include opportunities to discuss their wishes in relation to deactivation of the shock function of their device. If attempted prolongation of their life by their device is no longer appropriate or a priority for them, deactivation of the shock function may spare them (and those close to them) the distress and indignity of ICD shocks that have no useful purpose.

In the majority of people approaching the end of life consideration of ICD deactivation should take place at a time that allows planned deactivation for those who want it. The objective should be to avoid a person entering their last few weeks or months of life, even acutely or unexpectedly, without a care plan or without their views about device deactivation being known. Whenever possible, this should be anticipated and undertaken by the healthcare team that knows the person and not left, for example, to a hospital acute admission team.

Explaining and deciding about ICD deactivation

Obtaining consent from a person for treatment requires provision to that person of sufficient, intelligible information to allow them to make an informed choice. The possibility of a later need to deactivate an ICD and the reasons for doing so should usually be explained as part of the informed consent process prior to implantation in anyone considering an ICD or CRT-D device. The extent of information and explanation about deactivation needed will vary on an individual basis. In exceptional circumstances the clinician seeking consent may consider that providing information and explanation about future deactivation may cause harm, in which case the withholding of information and the reason for it should be documented carefully.

Decisions about deactivation of any device should be shared decisions, with full involvement of the person themselves and of the healthcare team caring for them, and must be based on careful assessment of a person's individual circumstances at the time. People should be given all the information that they need, both by verbal explanation and using written or other media, to allow them to participate fully in shared decision-making. Discussion of deactivation of an ICD as part of end-of-life care should allow ample time and opportunities for explanation and for an agreed, shared decision when the patient is ready to make it.

When people lack capacity, decisions must be made in their best interests, must be made according to the law in that jurisdiction and must involve those with legal power to make decisions on behalf of the person. The views of those close to the patient should be considered when making a best-interests decision in such circumstances.

Some important points to explain to people about ICD deactivation

Deactivating your ICD will not cause death.

Once your ICD has been deactivated, if you have a heart rhythm change that could cause death, your ICD will not deliver treatment for it.

Deactivating the shock function of your ICD does not deactivate its pacemaker function.

Deactivating your ICD will be painless. Near the end of your life your ICD may deliver shocks that are painful and distressing and are of no benefit.

If your condition improves unexpectedly or you change your mind the ICD can be reactivated.

It is best to think and decide about ICD deactivation in advance, rather than in a crisis.

Who should discuss deactivation?

The person who initiates a discussion will often be a healthcare professional closely involved in the person's care, who knows them and their clinical and home circumstances. Helping patients with end-of-life care plans is always a sensitive process and requires healthcare professionals to be competent in undertaking such discussions.

It may be necessary to involve several members of the healthcare team and to have serial discussions with patients and those close to them before reaching a shared decision with which they are comfortable. The appropriate members of the healthcare team to contribute to this will vary. In the vast majority of cases in which deactivation of a device is considered during life the consultant or senior clinician responsible for management of the patient's device should be involved in the decision-making process but the degree of that involvement or its delegation will vary according to individual circumstances.

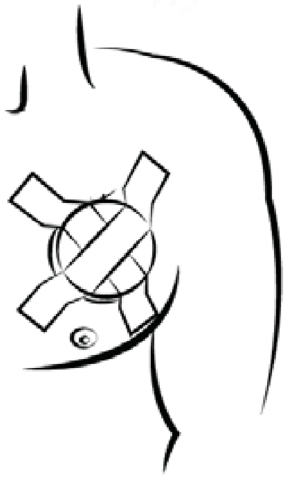
Depending on individual circumstances the healthcare professionals who initiate and undertake these discussions or provide support and information to patients and those close to them may include:

- **cardiologists**
- **heart failure specialist nurses**
- **arrhythmia specialist nurses**
- **cardiac physiologists (especially those involved in device management)**
- **general practitioners**
- **non-cardiologist physicians or surgeons**
- **palliative care doctors or specialist nurses.**

Emergency ICD deactivation

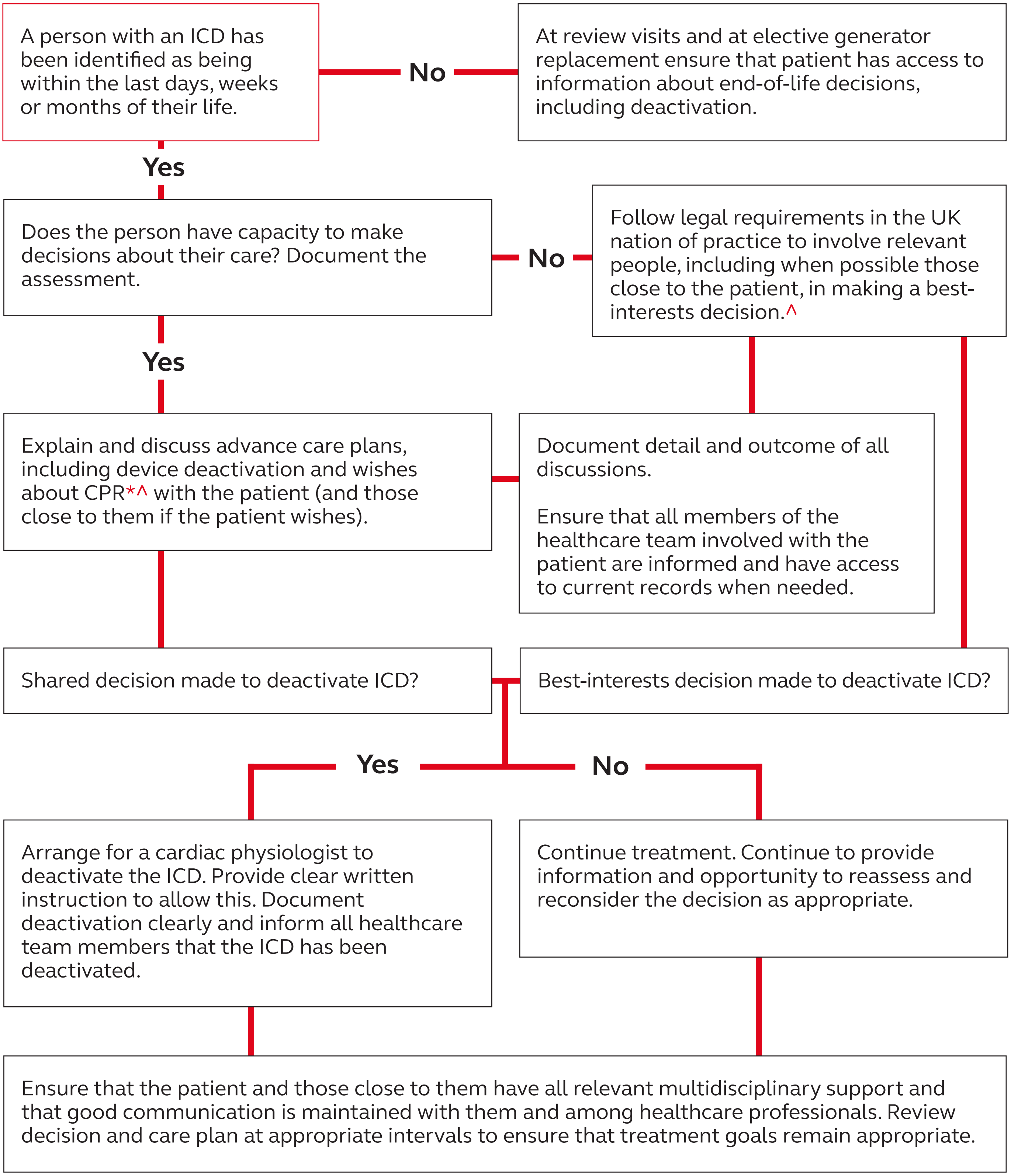
Situations may arise in which a patient is terminally ill, sometimes due to a sudden catastrophic event or sometimes where the question of deactivation has not been considered or determined in advance. In such situations, if urgent deactivation by a cardiac physiologist using a programmer cannot be arranged immediately, the ICD can be deactivated (after discussion and careful consideration of its consequences) by taping a ring magnet securely on the skin overlying the device.

Devices from one manufacturer (Biotronik) will be inhibited by a magnet for only 8 hours, so with a Biotronik device (or if the manufacturer is unknown) the magnet must be removed for a few seconds and then reapplied every 7 hours. When a magnet is used for emergency deactivation, arrangements should be made as soon as is practicable for definitive deactivation, using a programmer. Magnets for use in this way should be available in hospital departments such as Emergency Departments, Cardiology Departments and Cardiac Care Units and ideally in some other settings (e.g. hospices). Healthcare professionals who may need to undertake emergency ICD deactivation should ensure that they know where to access a magnet when necessary. A flow chart for emergency ICD deactivation is shown on page 7.



Resuscitation Council UK

Decision chart for ICD deactivation towards the end of a person’s life



A person with an ICD has been identified as being within the last days, weeks or months of their life.

No

At review visits and at elective generator replacement ensure that patient has access to information about end-of-life decisions, including deactivation.

Yes

Does the person have capacity to make decisions about their care? Document the assessment.

No

Follow legal requirements in the UK nation of practice to involve relevant people, including when possible those close to the patient, in making a best-interests decision.^

Yes

Explain and discuss advance care plans, including device deactivation and wishes about CPR*^ with the patient (and those close to them if the patient wishes).

Document detail and outcome of all discussions.

Ensure that all members of the healthcare team involved with the patient are informed and have access to current records when needed.

Shared decision made to deactivate ICD?

Best-interests decision made to deactivate ICD?

Yes

No

Arrange for a cardiac physiologist to deactivate the ICD. Provide clear written instruction to allow this. Document deactivation clearly and inform all healthcare team members that the ICD has been deactivated.

Continue treatment. Continue to provide information and opportunity to reassess and reconsider the decision as appropriate.

Ensure that the patient and those close to them have all relevant multidisciplinary support and that good communication is maintained with them and among healthcare professionals. Review decision and care plan at appropriate intervals to ensure that treatment goals remain appropriate.

* A DNACPR decision does not automatically warrant ICD deactivation and vice versa.

^ See “Cardiovascular Implanted Electronic Devices in people towards the End of Life, during Cardiopulmonary Resuscitation and after Death” and “Decisions relating to Cardiopulmonary Resuscitation” www.resus.org.uk.

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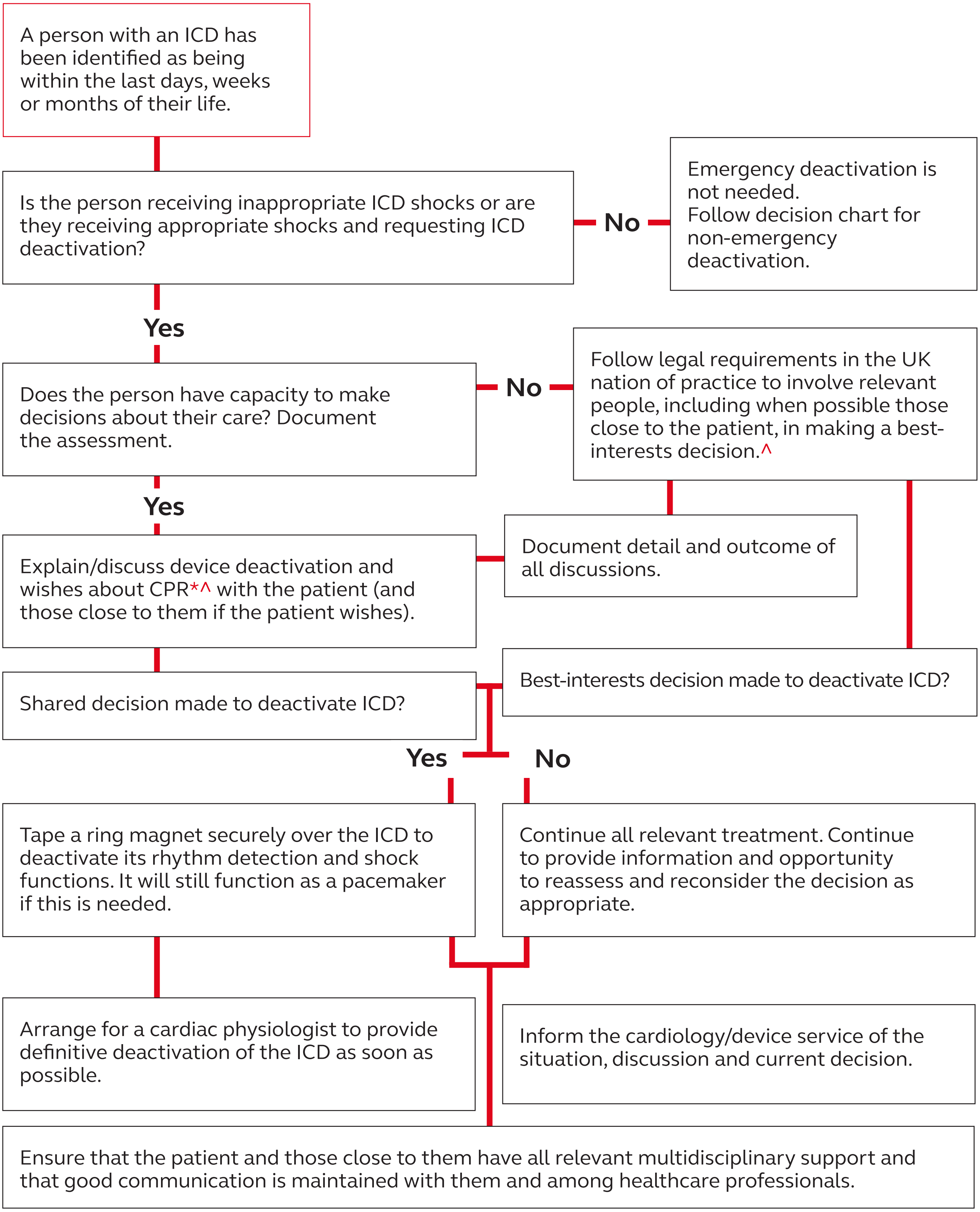
Decision chart for emergency ICD deactivation



A person with an ICD has been identified as being within the last days, weeks or months of their life.

Is the person receiving inappropriate ICD shocks or are they receiving appropriate shocks and requesting ICD deactivation?

No

Emergency deactivation is not needed.
Follow decision chart for non-emergency deactivation.

Yes

Does the person have capacity to make decisions about their care? Document the assessment.

No

Follow legal requirements in the UK nation of practice to involve relevant people, including when possible those close to the patient, in making a best-interests decision.^

Yes

Explain/discuss device deactivation and wishes about CPR*^ with the patient (and those close to them if the patient wishes).

Document detail and outcome of all discussions.

Shared decision made to deactivate ICD?

Best-interests decision made to deactivate ICD?

Yes

No

Tape a ring magnet securely over the ICD to deactivate its rhythm detection and shock functions. It will still function as a pacemaker if this is needed.

Continue all relevant treatment. Continue to provide information and opportunity to reassess and reconsider the decision as appropriate.

Arrange for a cardiac physiologist to provide definitive deactivation of the ICD as soon as possible.

Inform the cardiology/device service of the situation, discussion and current decision.

Ensure that the patient and those close to them have all relevant multidisciplinary support and that good communication is maintained with them and among healthcare professionals.

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* A DNACPR decision does not automatically warrant ICD deactivation and vice versa.

^ See “Cardiovascular Implanted Electronic Devices in people towards the End of Life, during Cardiopulmonary Resuscitation and after Death” and “Decisions relating to Cardiopulmonary Resuscitation” www.resus.org.uk.

Ethical and legal aspects

Consideration of ICD deactivation can raise concerns similar to those associated with the withdrawal of other life-sustaining treatments, such as renal dialysis or mechanical ventilation, or associated with decisions relating to CPR. Failure to give people information about their treatment choices breaches their human rights and breaches a fundamental principle of ethics, namely autonomy. Decisions about a person's treatment (including device implantation or deactivation) should be made jointly with any patient with capacity, following explanation of the balance of risks and benefits.

As people approach the end of their lives, especially if this is the first time that deactivation has been raised, such discussions are sensitive and often difficult for patients, for those close to patients and for healthcare professionals. This is not a valid reason to avoid discussions about these important decisions.

If a person with capacity requests withdrawal of treatment, despite being fully informed of the likely consequences, healthcare professionals must comply with that request, even when they consider the request unwise or illogical or when the withdrawal of treatment is contrary to medical advice,. Should an individual healthcare professional be unwilling to take action where there is a properly established decision to deactivate an ICD, it will be necessary to identify another healthcare professional to carry out deactivation.

Some people may be concerned that ICD deactivation could be interpreted as a form of assisted dying, and as analogous to voluntary euthanasia or assisted suicide. That is not the case. Voluntary euthanasia and assisted suicide each involve an active intervention that in itself causes the person's death. The courts have confirmed that, when death follows withdrawal of treatment, the person's underlying condition is deemed the cause of death. Such withdrawal will be lawful, provided that it follows from the person's competent refusal of treatment or, alternatively, is in his or her best interests. In such situations, the healthcare professionals are released from any duty to provide treatment.

Decisions about ICD deactivation and decisions about CPR

Decisions to deactivate an ICD and decisions about CPR attempts in the event of cardiorespiratory arrest are not the same. An assumption that having a DNACPR decision or being identified as dying automatically warrants ICD deactivation, or that ICD deactivation automatically warrants a DNACPR decision in every person is unethical. All decisions must be based on careful assessment of each individual situation.

In most cases, if there is an agreed decision with a patient or their representative that ICD shocks would present more burden than benefit, the same decision will be made about CPR, given that it is more traumatic and invasive, with less likelihood of a successful outcome. If it has not occurred already a DNACPR decision should be discussed at the same time as discussion of ICD deactivation. However, there may be occasional situations in which a person nearing the end of life will wish to be considered for CPR despite choosing to have their ICD deactivated, or having their ICD deactivated because it is delivering inappropriate shocks in the absence of ventricular arrhythmia.

Communication, documentation and care co-ordination

These are essential components of good medical practice. Failures of communication and documentation are common causes of complaint and litigation.

Good communication with patients and those close to patients should include provision of explanation and information, checking that these have been understood and answering any questions that people wish to ask.

Good communication among all members of the healthcare team (including usually the GP, the cardiology team and the palliative care team, and often other disciplines) as well as with the patient and those close to them is crucial to delivery of clear and consistent information and advice and ensuring that decisions are agreed and understood by all.

Details of discussions about ICD deactivation should be documented clearly in the person's health record. When an agreed decision is made to deactivate an ICD that decision and the reasons for it should be documented clearly. Documentation must provide all the information that the person (usually a device physiologist) who will carry out deactivation needs.

When an ICD has been deactivated it is crucial that this is documented clearly and communicated to all those who may need to know.

People with ICDs should carry with them current information about their device and, if it has been deactivated, this should be recorded clearly.

Further reading

Resuscitation Council UK, British Cardiovascular Society & National Council for Palliative Care 2014. Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death. Available at: www.resus.org.uk, www.bcs.com and www.ncpc.org.uk.

General Medical Council 2008. Consent: patients and doctors making decisions together. Available at: www.gmc-uk.org/publications/standards_guidance_for_doctors.asp.

General Medical Council 2010. Treatment and care towards the end of life: good practice in decision making. Available at: www.gmc-uk.org/publications/standards_guidance_for_doctors.asp.

The National Council for Palliative Care, Dying Matters and the British Heart Foundation 2014. Difficult Conversations. Making it easier to talk to people with heart failure about the end of life. www.ncpc.org.uk/sites/default/files/Difficult_Conversations_Heart_Failure_WEB.pdf